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ELADCOMM

EARLY INTERVENTION ADVISORY COMMITTEE OF THE

MASSACHUSETTS DEPARTMENT OF PUBLIC



GOVERNMENT DOCUMENT
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ANNUAL SUMMARY

FOR THE PERIOD JULY, 1989 THROUGH JUNE, 1990

Report of the Chairperson,
Early Intervention Advisory Committee,
to the Governor,
Commonwealth of Massachusetts
to the Secretary,
U.S. Department of Education
and to the Commissioner,
Massachusetts Department of Public Health,
persuant to M.G.L. Chap 111G

January 1991

INTRODUCTION

This report summarizes activities of the Massachusetts Department of Public Health Early Intervention Advisory Committee (EIADCOMM) for the year 1989-1990. The EIADCOMM also serves as the Interagency Coordinating Council (ICC) required under Part H of PL 99-457.

In accord with state law and statutory requirements under Part H of Public Law 99-457, the interagency committee performed the duties of advising and monitoring early intervention activities in the state. The EIADCOMM worked to coordinate the process of its activities between committees and with agencies. In addition it developed activities for its objectives and made recommendations to the lead agency .

Five major objectives for third year participation were to:

- broaden representation from the early childhood community on the EIADCOMM while at the same time bringing the EIADCOMM into compliance with the ICC as spelled out in PL 99-457 regulations
- draft policy recommendations for presentation to the lead agency, from discussions about developmental philosophies and conceptual models explored in EIADCOMM sub-committees
- explore options in the areas of child find, eligibility criteria, screening and assessment, Individualized Family Service Plan (IFSP) and case management services, in order to meet the requirements for year 4 funding
- examine options for funding early intervention services from other than state appropriated resources, in order to expand services to more children and their families
- foster parent participation in all policy recommendations and expand a network of active parent advisory councils

These objectives were achieved through the following planning process and operating procedures.

PROCESS

The activities of the EIADCOMM rely on active participation of the twenty five committee members who met for five full day meetings and participated in a two day intensive retreat.

The planning and development process of the group is carried out in task oriented committees designed to include a variety of constituencies representing programs, interests and skills. The current standing committees are: Standards, Fiscal, Program Development and Low Incidence Services. In addition, several

ad-hoc sub-committees were active in studying issues and recommending action in the areas of the Individualized Family Service Plan, Transportation, Public Awareness and ICC By-laws. Standing committees met monthly and reported regularly to the full EIADCOMM. Ad-hoc committees reported as requested. Each committee was chaired by a member of the EIADCOMM and staffed by personnel from the Division of Early Childhood, Massachusetts Department of Public Health. Committee membership draws from a broad base, including representatives from early intervention providers, parents, early childhood providers, state agency representatives and staff from Department of Public Health (DPH). This broad representation allows vigorous discussion to take place in the committees and sub-committees and affords opportunity for most issues to be resolved through this process.

The chairs of the standing committees met monthly with the chair of the EIADCOMM and representatives of the lead agency as a Steering Committee. This committee set agendas for the EIADCOMM meetings, assigned tasks to committees, and assured that processes were followed.

In addition, an internal working group of the lead agency, the Early Childhood Working Group was created. This group, which met every six weeks, included two members of the EIADCOMM as invited participants; the chair and an early intervention services provider.

OBJECTIVES

Expand membership of EIADCOMM; bring into compliance with ICC

Early in the year, the number of provider members of the EIADCOMM was increased to broaden input from the larger system of both private and public early childhood providers, such as home health care agencies, Easter Seal, and day care. Orientation for the new members required a significant effort on the part of the chair and committee leadership. Orientation is accomplished through printed materials, informal mentorship by the chair and other members, and recruitment to a committee or task force.

While strong efforts have been made to orient new members to the committee activities, experience has found this to be a complex issue. Most needed regular attendance and careful listening for almost a year before they became well informed about the system and felt comfortable enough to actively participate. They are now an integral part of the committee and respected for their contributions, on subcommittees, at hearings, and at the regularly scheduled meetings. Parents on the EIADCOMM also needed attention to become active participants. Even though they have or have had a child receiving services, it took time to become knowledgeable

about the policy issues being discussed and to understand the value and importance of their input into issues. Having more than the required three members as well as mutual support and mentoring by other parents and other committee members has strengthened active parent participation.

All EIADCOMM committees have made a significant effort to elicit and assure a balance of representation from Early Intervention Program providers, parents, representatives from state and private agencies that provide early childhood services, and the lead agency. Financial support for encouraging parent participation was initiated, and became a reality through funding provided by a Part H contract to the Federation for Children with Special Needs.

Members of the EIADCOMM met for a two day Constitutional Convention to review and revamp fundamental rules under which the ICC exercises its role. This afforded the environment in which to review processes and procedures used to date and to design new or modified processes for operation. The group identified clear cut goals, and followed through on the above stated task. This resulted in a common vision for the ICC, with the diverse members recognizing the strengths each individual brings. A strong task oriented working team was established. The result was a draft of new by-laws in order to bring the existing advisory committee into compliance with the federal regulations governing the ICC under PL 99-457. Effort was also expended in meeting the requirements of the state legislation and the federal regulations, particularly in the area of membership. The by-laws were presented to the EIADCOMM in the Fall of 1990 for ratification.

Recommend policies in areas required for fourth year application

Early in 1990 the EIADCOMM worked closely with the lead agency on a state definition of the criteria for eligibility to early intervention services. The EIADCOMM recommended continuation of a broad definition of developmental delay, as currently reflected in state law. This included children with diagnosed conditions and children "at risk" for developmental delay from biological and environmental factors.

The Program Planning Committee developed a vision of what would happen to a family once they were identified as potentially eligible for services. A schematic model of a system that described the process for a family from Child Find through Assessment was developed and later presented nationally at the Partnerships conference. (See page 5 of this report.)





*WIC
 LEA's
 DSS
 NICU's
 HRIS Hospitals
 Child Care
 Pregnant/Parenting
 Adolescent Programs
 Others

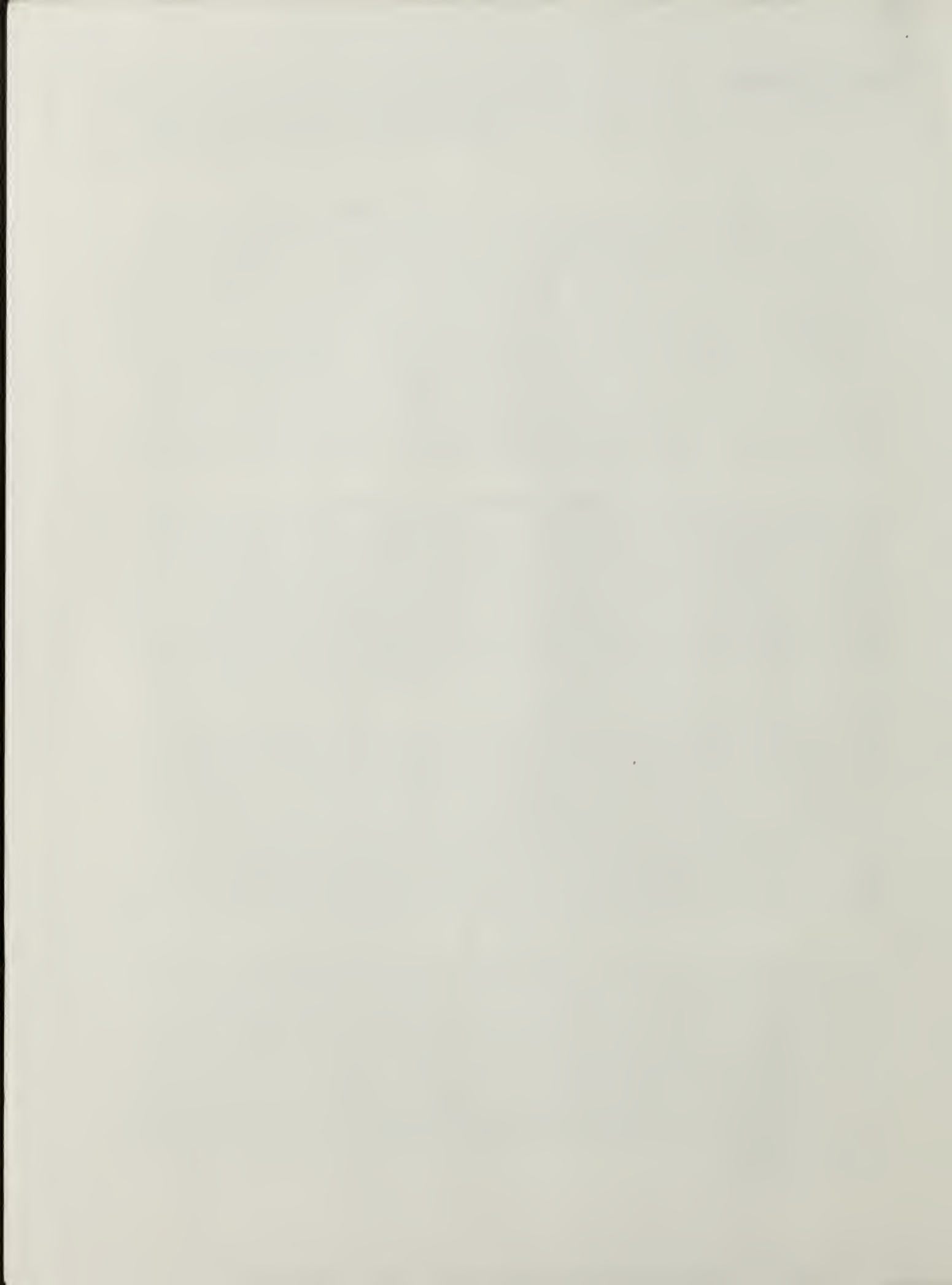


Concurrent with this work, a task force of the EIADCOMM worked to develop guidelines related to the components of the Individualized Family Service Plan, and identified three possible models for developing this plan. Members surveyed programs using these models, developed several philosophical issue papers related to the results, and presented to the EIADCOMM. The task force took care to have broad parent participation in developing recommendations in order to insure family concerns and priorities would be addressed in the IFSP. The EIADCOMM recommended a model to the lead agency which was approved as policy in the Spring. The care taken in the process of developing recommendations needs to be emphasized as well as the successful results of this task force. This process of careful study and extensive discussion is standard procedure for EIADCOMM task forces.

A task force to develop a case management system appropriate to support the implementation of the IFSP was formed. In each of these task forces, parents were active participants in the development of policy. Members discussed what families being served under PL 99-457 wanted and needed in case management as well as a review of system needs. The current system of case management for children with special health care needs in the Department of Public Health was studied. The task force developed clear criteria for where to refer families based on their needs, and recommended a three tiered system of case management under PL 99-457.

The Standards Committee of the EIADCOMM began an extensive review of the current Early Intervention operational standards governing certified Early Intervention programs in Massachusetts. Monthly meetings allowed a thorough review in determination of revisions to bring the standards into compliance with the Part H regulations promulgated in August 1989. The work of this and other task forces was accomplished by various members without expenditure to the lead agency. Instead of asking outside "experts" to offer recommendations and proposals, the EIADCOMM chose to develop most of the policy recommendations with members of the committee and broad consumer input from the public.

The Low-Incidence Committee explored and made recommendations relative to the impacts of policies and procedures within the annual state plan on blind, deaf-blind, deaf, autistic, and behavior-disordered children. The Committee conducted a survey, in collaboration with the Department of Public Health, of both early intervention and low-incidence providers. They looked at the impact of the Low-Incidence Pool on service provision to the above population of children and their families. The sign language training to parents continued to be implemented, and has seen a growing increase in the number of families, statewide, afforded this valuable service.



The Transportation Subcommittee spent considerable time reviewing the Department's policies with regard to the scope of services, safety standards, training requirements, monitoring of contract standards, and funding issues relating to transportation of infants and toddlers. The most important issue addressed repeatedly by this subcommittee has been need for transportation funding and the recommendation that the Department engage in long range planning which incorporates expansion in transportation funding with the anticipated growth of the Early Intervention service system.

Examine funding options for expanding Early Intervention services

The Fiscal Committee of the EIADCOMM took the lead in exploring funding options for support of Early Intervention services from other than state monies. This resulted in state legislation (Cpt 721) that mandated private insurance plans to provide coverage for medically necessary early intervention services. Implementation was begun in the second half of the year after extensive negotiation between the lead agency, insurers and providers. The EIADCOMM provided education to providers and parents on the meaning of this policy in the writing of IFSPs, what services are covered as "medically necessary early intervention services," and managing deductibles and lifetime capitation, which was a concern for some parents.

Concurrent with implementation of third party payment was an open discussion of the use of sliding fee scales. This topic was explored with multiple viewpoints expressed. The lead agency conducted a survey, and parents surveyed their constituencies. Providers suggested various options with differing recommendations. Two open forums were held for full discussion by all interested parties before the issue came before the EIADCOMM for a vote. Following a two year study, the presentation of information to the EIADCOMM in May 1989 and hearings conducted by DPH in December 1989, the EIADCOMM voted in January 1990 to recommend that a sliding fee scale should not be implemented.

"Resolution: Based on the continuing issue that a mandatory fee for service system does not seem to meet the accessibility requirements of PL 99-457 and Mass. Law Chapter 11-G, and the potential influx of revenues under the third party insurance bill and the proposed 89-313 regulations which do not allow a fee for service system, the EIADCOMM recommends that a fee for service system to Early Intervention services in Massachusetts not be implemented at this time."



Foster parent input into policy making and develop a network of parents to support implementation of PL99-457

Using the parent members of the EIADCOMM as key players in linking to Parent Advisory Councils (PACs) in their regions, issues discussed in advisory meetings were taken to regional meetings of PACs for input and further discussion. This was particularly effective in three out of the five regions of the state. Additionally, newsletters among and between regional PACs were supported by EIADCOMM funds, and a first annual state wide meeting of parents was held at the Massachusetts Early Intervention Consortium conference. Both financial and technical assistance support was provided to EIADCOMM parent members to enhance their effectiveness as leaders of the fledgling network of parents and to support efforts of the lead agency and the EIADCOMM. An essential element of this plan is to work through the state wide advisory committee parent representatives to the regional and local parent advisory councils. While this process is slowly being established, it should be quite strong after another year of development.

Other significant efforts of advisory committee during this year

In order to further the work of the objectives set for this year, the EIADCOMM encouraged the following advocacy efforts. Support was given to the Massachusetts Early Intervention Consortium as they worked for passage of the insurance bill. Individual members of the EIADCOMM also testified for the increased funding for Early Intervention in Massachusetts.

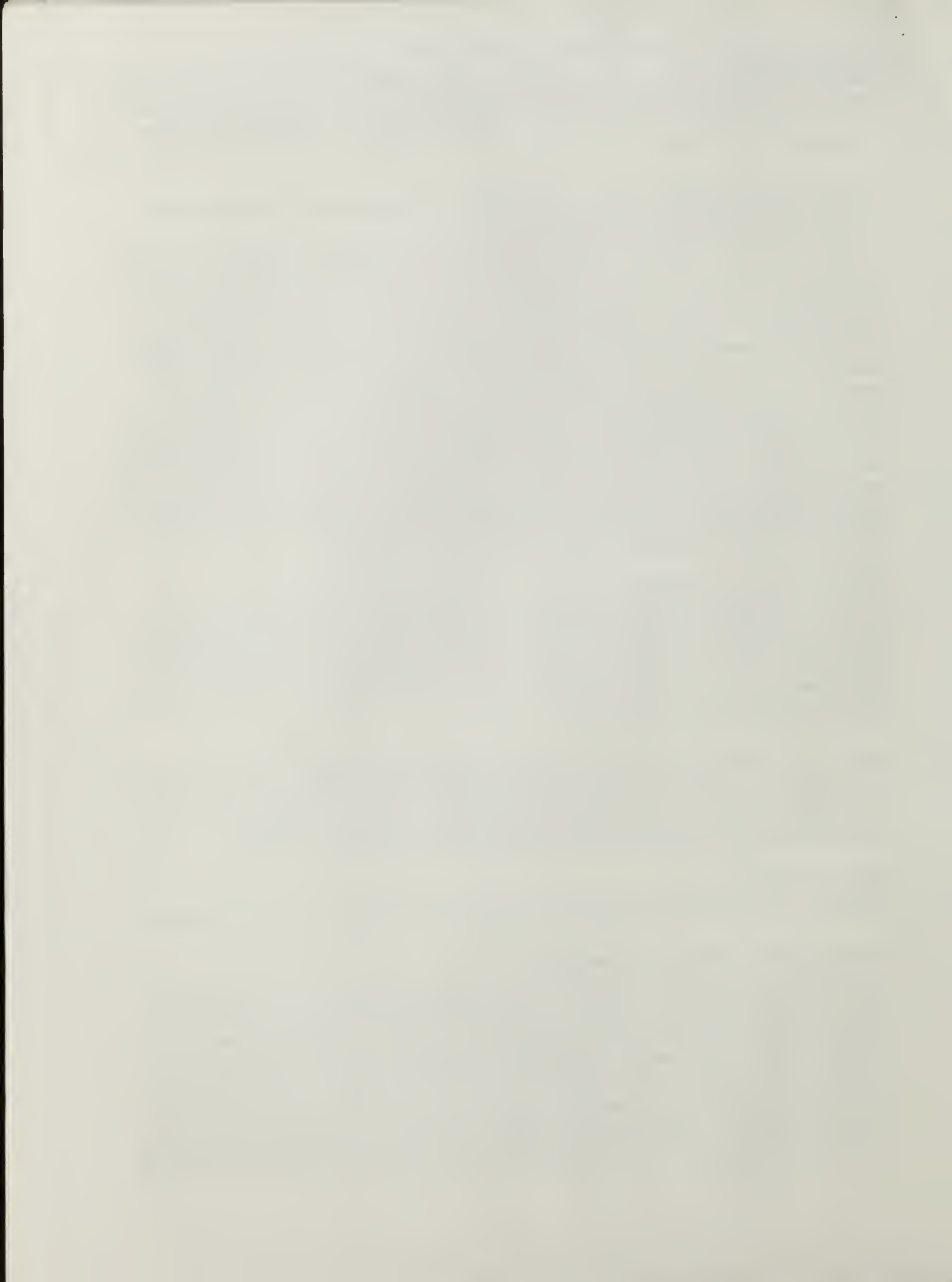
Additional advocacy efforts were provided through letters and personal contacts on the national level when the House of Representatives suddenly recommended the combining of PL 89-1313 monies with preschool monies. This would have had significant negative effect on the early intervention system in our state.

CHALLENGES

Implementation of PL 99-457 continues to present challenges for the committee.

Families and Children Need Services

The health care community appears to increasingly understand and recognize the value of early intervention services. An increasing number of children and families are being referred to programs. However, those who are referred for early intervention services in the state are unable to receive these services in all areas of the state in a timely fashion. This results in these children and families either waiting for services or obtaining fragmented discrete services while awaiting a comprehensive team program. As planning takes place for fourth and fifth year requirements there is grave concern of the availability of quality services to meet the expectation



of entitlement (i.e. entitlement in fourth year to referral for multidisciplinary assessment and formulation of an IFSP, and entitlement to full services in fifth year.)

The funding resources for early intervention services limit the rate of growth. Insufficient federal dollars in tandem with limited state dollars have curtailed the system. While the third party insurance bill was passed in January 1990, it is taking several months for processes to be put in place before programs can realize these dollars. Restricted funds impact on salary compensation for professionals working in early intervention and these hamper attracting and maintaining adequate personnel. In addition, qualified professionals are unavailable in all disciplines to meet the service demand.

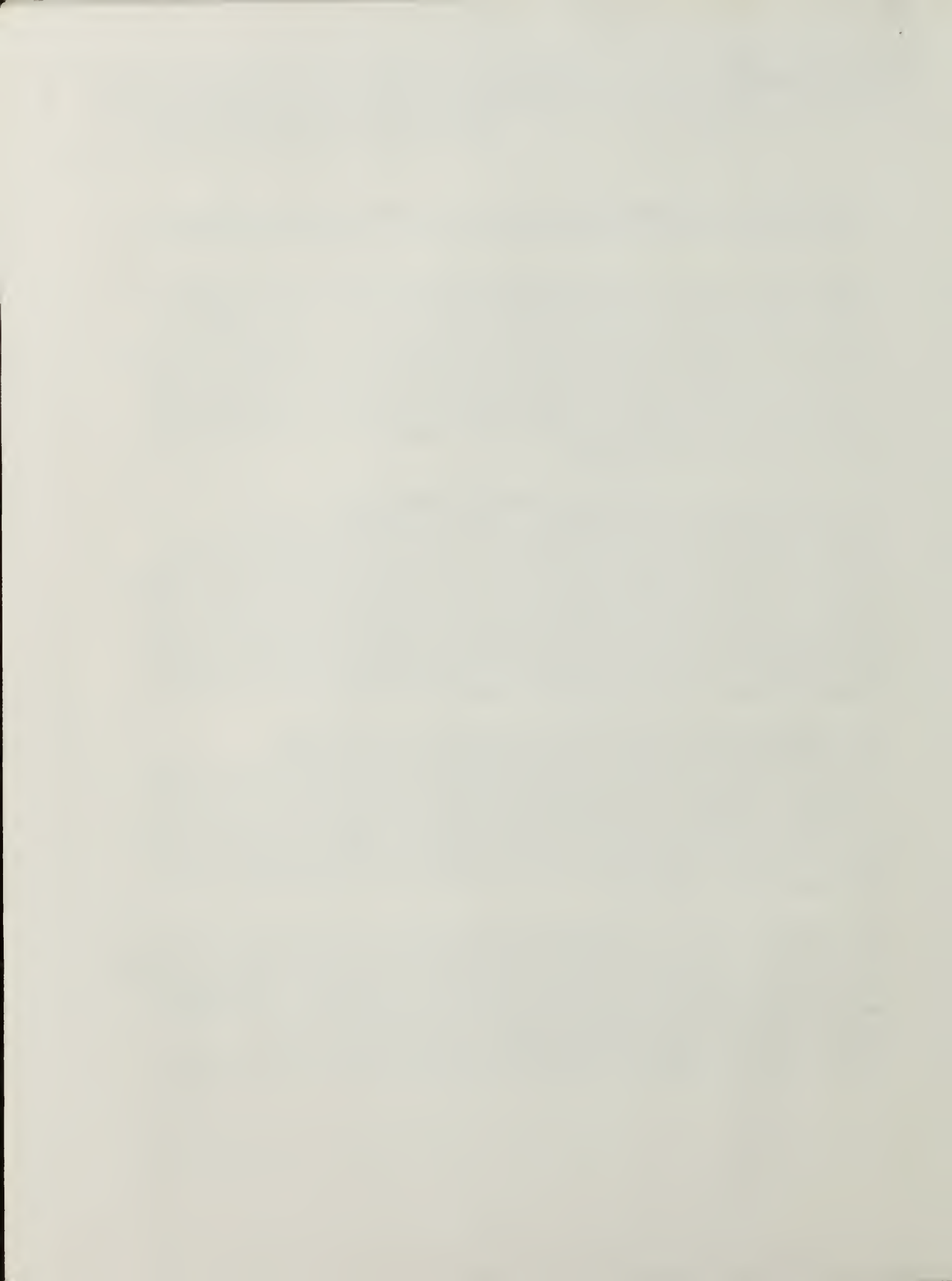
Policy development can't keep up with the funding cycle

In order to keep up with the timelines of the federal granting cycle, the EIADCOMM has had to do a tremendous amount of work to meet the requirements necessary for implementing the fourteen components outlined in the regulations of PL 99-457. Even in a state with an existing system of services as in Massachusetts, there has been too much to do in a limited period of time to meet the grant application timelines. Members of the EIADCOMM consistently struggle with feelings of a lack of completeness in recommendations; there is a need for further refinement and not enough time to process the material.

Knowledge of how to use and access interagency coordination

The EIADCOMM has worked to inform the public, the legislators, and the early childhood community of its work, yet there appears to be limited use of this body to both plan and address concerns within the system. Legislators and governing bodies appear aware of early intervention as a system, but have limited knowledge of the interagency strength the advisory committee has in coordination of early childhood services in the state.

The committee collaborates efficiently and productively with the lead agency and its staff. There is coordination, a great deal of discussion, and collaboration among the members of the EIADCOMM and the agencies represented. The challenge facing the EIADCOMM in the coming year is to make the public aware of this strength as well as the potential role it plays in the development of a family-focused, community-based coordinated early childhood service system.



THANKS

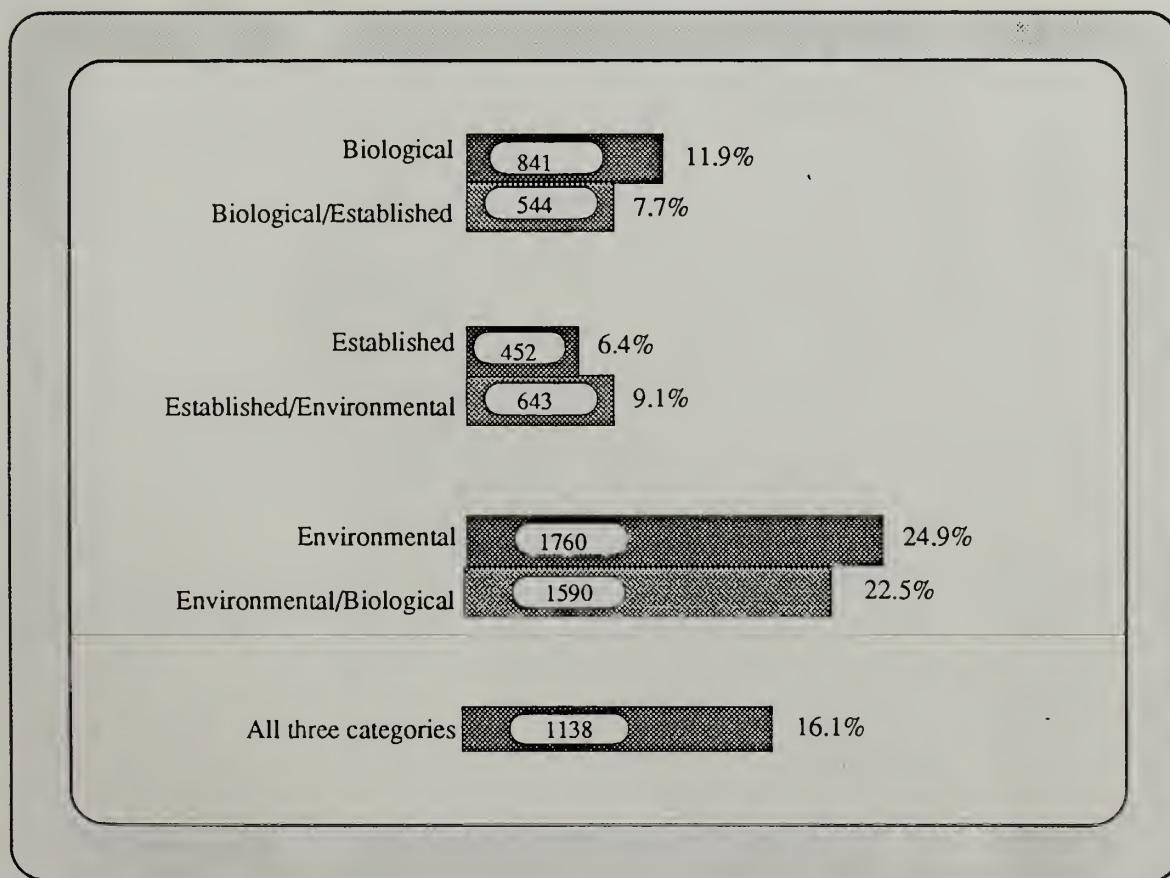
The chair of the Advisory Committee, Eunice Shishmanian, has been consistent since 1985. She wishes to thank the following members of the EIADCOMM who have served during this third year of planning for implementation, a particularly busy year since the federal regulations were publicized.

Members serving July 1989 through June 1990

Delinda Anderson	Early Intervention Provider
Karen Edlund	Department of Public Welfare
Rosalie Edes	Parent
Linda Edwards	Early Intervention Provider
Marie Esposito	Cambridge Visiting Nurses Association
Linda Fox	Parent
Peggy Freedman	Mass. Developmental Disabilities Council
Ediss Gandelman	Early Intervention Provider
Grace Healy	Department of Mental Retardation
Karl Kastorf	Department of Public Health
Betsy Leutz	Early Intervention Provider
Carol Lennon	Parent
Beverly Levangie	Local 509
Anne Linehan	Infant/ Toddler Provider
Barbara McCauley	Parent
Tom Miller	At Large
Amira Pellett	Growth and Nutrition Clinic
Judith Presser	Office for Children
Elisabeth Schaefer	Department of Education
Kathleen Selvaggi	Franciscan Children's Hospital
Eunice Shishmanian	UAP, Children's Hospital
Sandy Slavet	Parent
Ann Taylor	Early Intervention Provider
Harri Thibeault	High Risk Infant Program
Karen Welford	Early Intervention Provider

DATA FOR YEAR III

7,066 children received early intervention services in 1989.
This represents a 2.3% increase over the previous year.



Total 98.6% 7066

